Privacy and Security Testimony
Illinois Health Information Exchange Authority
July 17, 2012

Global Patient Identifiers Incorporated (GPII) appreciates this opportunity to submit verbal and written testimony to the Illinois Health Information Exchange Authority (ILHIE) concerning health data privacy and security policies. We commend the organizers of this effort for so clearly enunciating many of the important issues requiring resolution. Our testimony will not address your policies *per se*, but rather one critical aspect of the methods required for implementing privacy and security: the unambiguous identification of individuals.

GPII is a healthcare nonprofit company[1] dedicated to the deployment of unique individual healthcare identifiers. These identifiers are based upon ASTM international/ANSI standards and, with enhancements, have several functions: 1) accurate identification of each individual for every medical encounter; 2) enhanced privacy management of clinical information; 3) facilitated anonymization and 4) unambiguously identifying the location of medical information wherever the standard is deployed.

HIGH LEVEL STRATEGIC RECOMMENDATIONS

- ILHIE adopt the ANSI/ASTM E2553-07[2] and E1714-07[3] standards to internally identify individuals, some of whom will be patients. For discussion purposes we will call this the ILHIE unique health identifier (IL-UHI).
- ILHIE coordinate with Federal and other states to encourage their adoption of this standard.
- ILHIE should coordinate with the Veterans Administration, which has already adopted this standard, to integrate VA patient identifiers and avoid duplications.
- ILHIE deploy an implementation of these standards which incorporates privacy classes, permitting more robust management of individual preferences and privacy policies.
- ILHIE provide a platform for all providers in the market to utilize IL-UHI as their internal identifier and in transactions using ILHIE.
- ILHIE issue IL-UHI cards to individuals who are incorporated into the ILHIE Master Patient Index. Such cards can be co-branded with provider organizations.
- ILHIE utilize a national UHI registry to determine where UHIs have been issued and used. This national registry will not be able to identify specific individuals associated with an IL-UPI. This service is currently available from GPII[4].
- ILHIE expenses to manage IL-UHI will be offset by end user fees at a cost much less that their current expenses to manage patient identification[5].

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[1] GPII is registered as a taxable non-profit corporation in the state of Arizona.
[2] http://www.astm.org/Standards/E2553.htm
[3] http://www.astm.org/Standards/E1714.htm
[4] http://www.gpii.info
[5] Case Study: Patient Matching: Sharp HealthCare's Journey, William Spooner et al, June, 2012.

WHAT PROBLEMS DOES THIS TESTIMONY ADDRESS?

The solution described in this testimony allows ILHIE to virtually eliminate patient identification errors. Current Enterprise Master Person Index (EMPI) technology can achieve roughly 3-sigma levels of patient identification accuracy. ILHIE will require roughly 6-sigma accuracy to achieve sustainable operations. The Voluntary Universal Healthcare Identifier (VUHID) solution offered by GPII enhances the performance of existing EMPI products to achieve 6-sigma performance. It can be used by ILHIE to implement a single uniform privacy policy across all ILHIE facilities and/or to support concurrent operation of multiple independent privacy policies. VUHID identifiers enable anonymous data reporting for uses such as public health, quality assurance, medical education, and medical research. They provide a data location facility that enables any ILHIE caregiver to assemble an accurate, error-free comprehensive medical record for a patient based on all the information contained throughout ILHIE and respecting that patient's privacy wishes as implemented by ILHIE. VUHID identifiers also position ILHIE to participate seamlessly in the Nationwide Health Information Network from a patient identity perspective.

DETAILED RECOMMENDATIONS AND COMMENTS.

- The error rate for patient identification within ILHIE must approach zero. It will not be possible to gain public trust in the ILHIE system unless patient identification is exceptionally accurate – more accurate than is possible with an unaided EMPI system.
- Identification solutions must **both** promote information sharing and protect privacy. You cannot choose one over the other and have a system that is trusted and functional.
- Patients must be able to sequester specific portions of their patient record. The specific sequestering options must represent a combination of patient preference, applicable laws and regulations, including those emerging from the current process.
- Our recommendations can support either opt-in, opt-out or hybrid systems for patient consent.
- Public health reporting requires submission of specific reportable data. With a trusted system, patients might consent to additional submission options that are otherwise constrained by applicable law. That information could also be made available on an anonymized basis.
- Our recommendations can support patients' ability to withhold certain information from a physician encounter and policies managing physician awareness that this is happening.
- Our recommendations can support a "break the glass" option and mechanisms to restore patient's previous privacy constraints once the emergency is over.
- ILHIE policies can incorporate the VUHID privacy classes to create a more robust system. Privacy classes can include the four categories of sensitive data noted in the Panel Three examples. Additional privacy classes can expand the types of information under patient privacy control.

- Our recommendations can facilitate analytics and reporting based on privacy classes, helping garner public education and trust.
- Formal legally valid consent documents can incorporate VUHID privacy classes linked to patient constraints and then implementation using a real-time point of care electronic systems.
- VUHID can help locate consent documents wherever the standard is implemented. Each medical encounter can then respect the constraints currently in place. Our recommendations mitigate the risk of identification error that might result from retrieving the wrong patient consent documents.
- The use of a unique patient identifier represents the only practical approach to achieve the accuracy required by the ILHIE: an error rate approaching zero. Further, this accuracy can extend beyond ILHIE geographic boundaries.

Global Patient Identifiers Incorporated wishes to express its thanks to the Illinois Health Information Exchange Authority for the opportunity to submit this testimony concerning its patient electronic health data privacy and security capabilities. We would welcome any questions or communications aimed at further clarifying the statements we have made here.

Respectfully,
David Stumpf and Barry Hieb representing GPII